

**Little Hoover Commission Testimony  
Children and Mental Illness  
To be Presented at A Public Hearing on Children's Mental Health Policy  
October 26, 2000, State Capitol, Sacramento**

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**Introduction**

I am pleased to be able to testify today regarding children and mental illness. I would like to add my voice in praising the Little Hoover Commission for addressing this important, and historically, overlooked topic. My goals today are to briefly provide an overview of the prevalence of mental illness among children and of the current knowledge base regarding the effectiveness of services provided to children with mental illness. I will try to make every effort in my presentation to be accurate in my comments, however, as in all things, there may be inaccuracies in how I understand or interpret the research literature. There may, as well, be differences of opinion between my interpretation of the facts and those of my colleagues. When possible, I will attempt to err on the side of being vaguely right as opposed to precisely wrong. With these caveats out of the way, I will begin with a brief overview of the current knowledge base regarding the prevalence of mental illness among children.

**Prevalence of Mental Illness Among Children**

Prevalence rates for mental disorders among children and adolescents are typically assessed using by a combination of meeting diagnostic criteria for a mental disorder along with having functional impairment that impacts on the capacity of the youth to function in at home, in school, and in the community. Prevalence rates for mental disorders consequently vary depending on the level of impairment experienced by the child. The current consensus from the existing research base is that almost 21 percent of the children in the United States ages 9 to 17 have a diagnosable mental disorder combined with at least minimum impairment. The rates for specific disorders combined with minimal levels of impairment are: Anxiety Disorders, 13%; Mood Disorders, 6%; Disruptive Disorders, 10%, and Substance use Disorders, 2%. These numbers add up to more than 21 percent because youth can have more than one disorder.

If, however, *significant* functional impairment is required to make a diagnosis, then the prevalence rate drops to 11 percent. This estimate translates to 4 million youth in the United States who suffer from a major mental illness that results in significant functional impairment at home, at school, and with peers. If extreme functional impairment is considered as the criterion, then the estimates drop to 5 percent.

In addition, the term Severe Emotional Disturbance is often used to characterize those youth who have the most severe disorders and levels of functional impairment. The Substance Abuse and Mental Health Services Administration, Center For Mental Health Services (SAMHSA, CMHS), places the estimate for severe emotional disturbance at 5% to 13% nationwide. These figures overlap with the most current epidemiological data for prevalence rates where prevalence is defined as having a mental disorder and significant (11%) to extreme (5%) levels of impairment.

The bottom line is that, currently, 5% of the youth in this country have an emotional disturbance that can be termed extremely severe. Up to twice as many youth have emotional disorders that impact in very serious ways on their capacity to function in the real world.

Prevalence rates do vary by age. In a recent review of the literature on prevalence of psychopathology among children and adolescents, we found across 52 studies over the past four decades that studies of prevalence that median rates for the existing literature of mental disorder are: 8% for preschoolers, 12% for pre-adolescents, 15% for adolescents, and 18% in studies including wider age ranges. In addition, prevalence rates for mental disorders to seem associated with poverty, especially multi-generational poverty. Other risk factors for the prevalence of mental disorders include: physical problems, intellectual disabilities, low birth weight, family history of mental and addictive disorders, caregiver separation and abuse or neglect.

### **Prevalence Estimates for California**

It is difficult to obtain precise estimates for the prevalence of mental disorders in California because studies of community prevalence have not been conducted in this state. However, it is possible to make estimates by applying the national rates of mental disorder to California. It has been suggested by work done through the Substance Abuse and Mental Health Services Administrations Center for Mental Health Services, that the prevalence rate for severe emotional disturbance be at the high end of the national range in California due to the relatively high level of poverty of the children in California.

It is probably best to think of prevalence rates in California as falling between a range, from a low, conservative estimate to a higher estimate. National data would indicate that the range for severe emotional disturbance in California should fall between five to thirteen percent of the youth currently residing in the state. United States 1990 Census projects estimate that 10,000,000 persons under the age of 18 live in California. Given national prevalence estimates, it is likely that between 500,000 to 1.3 million children in California have a severe emotional disturbance. All of these youth could be classified as having "need" for mental health services.

## **Access to Services and Unmet Need**

Because of limited data, it is also difficult to truly assess the level of unmet need for mental health services in California. National data point to clear evidence of unmet need and problems in the access of mental health services for children and adolescents. In a multi-site survey funded by the National Institute of Mental Health, slightly more than half of the youth with a diagnosis and at least minimal levels of impairment received no treatment in any sector of the health care system. Youth enter mental health services through a variety of portals. In this same survey, the majority of those who did receive mental health services, received them from the schools or the human services sector with no specialty health or mental health services.

In California, as in the rest of the country, youth who receive public mental health services also receive services from other components of the human services system, including social welfare, juvenile justice, education, and primary health care. Statewide data are, unfortunately, not available for youth across service delivery systems. However, some counties have been able to merge information across multiple service sectors. In addition, data is also available regarding the degree of overlap between the foster care and mental health systems for the 1995-1996 fiscal years, with more current data currently being analyzed.

From these selected data sets, we have learned that in 1995-1996, approximately one third of the youth in Foster Care received public mental health services (less than the 50 to 66% of the youth in Foster Care who likely have need for such services). With regard to juvenile justice and mental health, in Sonoma County, we found that 20% of those youth receiving public mental health services had recent arrest records and 30% of all youth arrested had received public mental health services. Over 80 percent of the youth who receive public mental health services in Santa Cruz County also receive services from other human service sectors.

Finally, data on the number of youth who receive mental health funded through private sources such as insurance or out-of-pocket payments are difficult to gather. In sum, although it is possible to estimate the number of youth in California with mental disorders, and it is possible to determine the number of youth who receive public services, it is difficult to determine unmet need because youth may receive privately funded services or may receive mental health services outside of the specialty mental health system.

Recently, the California Mental Health Planning Council engaged in an effort to obtain estimates of unmet need for California by examining levels of need for mental health services, the numbers of youth receiving public services, and making informed assumptions regarding the numbers of youth receiving private sector services. Without going into detail, I would consider their estimates to be quite conservative but definitely worth considering from a policy perspective. By their estimates, some 128,000 youth in

California are not receiving needed services by their most conservative estimates. Using less conservative estimates lead to the conclusion that over 800,000 youth are not receiving services.

Finally, the use of public mental health services does vary by age, gender, and ethnicity. In most counties, children who are African American are in the public mental health service systems in higher proportions than would be expected given their representation in the population at large. Asian Americans are under-represented relative to their representation in the population at large and Latino-American representation varies by county. The youth in the public mental health system also tend to be older and male. These differences are not necessarily indicative of the level of need across ethnicity, age, or gender and probably represent differences in how services are accessed.

### **Effectiveness of Services**

There is a voluminous literature regarding the efficacy and effectiveness of services delivered to youth with mental disorders. It is important to note that a great deal of the existing knowledge base examines the efficacy of treatments, whether treatments work in controlled clinical settings. There is relatively less literature on the effectiveness of treatments, whether treatments work in real world clinical settings. Addressing this gap between the kinds of treatments that exist in controlled settings such as University based clinics and the kinds of treatments that are actually provided in real world settings such as public mental health systems is currently the focus of much attention nationally and research is underway to address these gaps.

For sake of simplicity, I will group the literature on the effectiveness of services into three general categories. The first, practice level research, is focused on what caseworkers or clinicians actually do when treating youth with mental disorders. The second level, program research, is focused on constellations of treatments that can be grouped into programs. The third level, service systems research, focuses on the organization and financing of the service delivery system.

### **Practice Level Effectiveness Research**

Much of the practice level research on mental health services to children and adolescents has focused on the efficacy of various treatment interventions for a variety of specific disorders. In general, these treatments are designed for specific diagnostic categories, such as depression, anxiety, ADHD, and conduct disorder. Such research focuses predominantly on the efficacy of various forms of outpatient psychotherapy such as cognitive behavioral therapy and on the efficacy of various forms of medication, often combined with psychotherapy. The literature is voluminous and defies brief summarization. However, recent meta-analyses of psychotherapy for children age 4-18, concluded that the average treated individual was better adjusted after treatment than 79% of those not treated. In a summary article, it was noted that, among youth: (a)

psychotherapy appears to be more effective than no treatment, (b) the magnitude of the effects closely parallels those obtained with adults, and (c) treatment differences, when evident, tend to favor behavioral rather than non-behavioral techniques. These cumulative findings provide support for the *efficacy* of outpatient psychotherapy interventions provided to children presenting with specific mental health problems and behavioral disorders. However, the *effectiveness* of such interventions, when provided in community settings to children is much less well understood or documented. Further, there are many barriers to providing treatments that are proven efficacious to real world clinical settings, including the level of severity of problems faced by youth who receive public mental health services and the level of training, supervision, and time necessary to implement the types of detailed practice protocols that are common in the research environment.

### **Program Level Interventions**

Recently, Barbara Burns and her colleagues conducted an exhaustive review of the existing literature base on the effectiveness of a range of interventions for youth with mental disorders. This review provides the best summary to date of the effectiveness of what can be termed program level interventions and will form the basis for my comments.

There are wide ranges of potential interventions for youth with mental disorders. In general, the authors of the review highlight a series of methodological problems with much existing research, including, most importantly, the reality that many studies reflect interventions that do not typify clinical practice and that empirically validated treatments, such as a range of outpatient psychotherapy approaches, have been tested on children and families who do not generally represent clinic referred children.

The authors do report that the strongest evidence for positive outcomes include: home based services, therapeutic foster care, some forms of case management, and pharmaceutical and psychosocial treatments for specific syndromes. Importantly, the conclusion of the effectiveness of home-based services is largely based on the results from Multi-Systemic Therapy, which is a very specific form of treatment for youth who have conduct and other disruptive behavioral disorders.

The studies on case management do include the use of wraparound processes, which are currently popular in California. The authors conclude that there is encouraging evidence regarding the effectiveness of the wraparound process. Part of the difficulty of assessing the effectiveness of wraparound has been providing consistent definitions of the process. Progress is being made on this front, and considerable research activity on the wraparound process is likely over the next several years.

Research on traditional outpatient treatment suggests the strongest results for psychosocial treatments that focus on problem solving strategies, on parent management training, and on strengthening child-parent interpersonal skills. The authors also make a

strong case for the need for family engagement in treatment, asserting that the effectiveness of services probably hinges on when and why families are engaged in the treatment process.

### **Service System Research**

The majority of system level research in the past decade has focused on the system of care approach for youth with severe emotional disturbance. In response to reports documenting that mental health services have often been inadequate for meeting the complex educational, social, and developmental needs of children with severe emotional disturbance and their families or caretakers, attempts to remedy the dual problems of access to care and quality of care have occurred at federal, state, and local levels. The National Institute of Mental Health developed the Child and Adolescent Service System Program (CASSP). CASSP was designed to provide assistance to states and communities to develop comprehensive, coordinated systems of care for children and adolescents with severe emotional disturbance. A guiding principle in these efforts is the focus on interagency collaboration and service integration.

California has been a national leader in the development of the system of care approach. The system of care model that is currently being implemented throughout California is the largest, in terms of size, scope, and number sites, replication of a single system of care model in the country. The Center for Mental Health Services has provided grants to over sixty sites, including a dozen California Counties, to create interagency systems of care.

A year and a half ago, I completed a review of the national system of care literature. I found that the existing research on systems of care was very difficult to evaluate critically, as much of the research had not been published. I found strong positive results for system level outcomes across 18 studies nationwide, including reductions in the utilization of restrictive levels of care. Also, across a range of domains, youth with severe emotional disturbance did show improvement.

However, the Fort Bragg Study found higher costs in the demonstration "system of care" site than a comparison. Also, the study found that youth in the comparison site did not differ from the demonstration site in terms of improvements across a range of measures of clinical and functional status. The Fort Bragg study has been extremely controversial, especially regarding how the results from the study should be interpreted. The completion of a study in Stark County Ohio, which found similar results and was conducted by the same investigator who completed the Fort Bragg study, added yet more fuel to the debate.

Some have argued, based on the results from Fort Bragg and Stark County that the System of Care approach does not "work". Others have argued that the Fort Bragg and Stark County studies are flawed, and that the results are of limited value cannot be generalized. Both extremes of the argument are problematic and oversimplify a complex set of research

findings. I believe the United Surgeon General's report on mental health provides the most balanced summary of the current status of system of care research:

"The multiple problems associated with serious emotional disturbance" in children and adolescents are best addressed within a "systems" approach in which multiple service sectors work in an organized, collaborative way. Research on the effectiveness of systems of care shows positive results for system outcomes and functional outcomes for children; however, the relationship between changes at the system level and clinical outcomes is still unclear."

This conclusion also fits our research on systems of care in California. We have found that longstanding system of care sites in California show positive system level outcomes. This includes controlling residential placements, reducing juvenile justice recidivism, and improving educational achievement. We have also found that new system of care sites are varying both in how they implement the system of care model and in the system outcomes that they achieve. We do find improvements in functional status for system of care counties, but cannot conclude that these improvements are due to system level changes.

### **Concluding Comments and Recommendations**

I would like to thank the Little Hoover Commission for this opportunity to provide this testimony. I hope my testimony provides evidence that large numbers of children have mental disorders that many if not most of these children do not receive needed services, and that, while much progress has been made, much remains to be understood regarding the effectiveness of services to these children and their families.

As someone who conducts research on the services to youth with severe emotional disorder in California, I am continually inspired by the hard work and perseverance of people who provide and administer services and by the strength and courage of the children and families who receive these services. However, there remains considerable need for a better information infrastructure and information regarding children's services. Cross agency data systems do not exist. It is not currently possible, for example, to routinely document the relationships in the types of mental health and social welfare services provided to youth. There is no statewide juvenile justice information system that tracks youth at the individual level. Educational data is similarly lacking statewide. Data on private sector services are proprietary in nature, and extremely difficult to access. It is almost always difficult or impossible to merge data across the adult and child service sectors.

Consequently, it is either impossible or exceedingly difficult to answer essential questions statewide regarding the services to youth with severe emotional disturbance. Such questions include: How many youth statewide who receive public mental health services also are in the juvenile justice system? What is the educational attendance of

youth who receive mental health services? How many of these youth graduate from High School? How many youth receive mental health services from non-mental health providers, such as probation officers or CPS caseworkers?

Many other questions could be routinely answered if necessary data systems were in place statewide. Although many barriers certainly exist in the development of such systems, other states have had some degree of success and are able to address such questions. As I worked on this testimony to answer the questions of the Commission, I was continually struck by how better statewide information would better inform the policy process.

Finally, over the past decade, the field of children's mental health has evolved considerably. A decade ago, resources were extremely scarce. Interagency collaboration in the provision of services was rare, and children's mental health received little attention from policy makers. That has changed, both in California and nationally. It is my sincere hope that the report being prepared by the Little Hoover Commission can continue to keep the needs of children with mental disorders and their families visible in California state policy. It is also my hope that the progress that has been made in the delivery of services to these children and families in California can form the foundation for solid growth so that these children and families can have a brighter future.

Thank you.